

Community Capacity Building Project 2001-03
Implementing a Virtual Community for
Breast Cancer Information and Support in Ontario
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PROJECT SUMMARY

In 2000 the Ontario Breast Cancer Information Exchange Partnership (OBCIEP), a coalition of organizations who have a stake in the dissemination about breast cancer, proposed a model for a breast cancer virtual community. A virtual community for breast cancer information and support uses web-based technology and tools such as bulletin and resource boards, hyperlinks to other sites, e-mail exchange, chat rooms, and document libraries to enhance the collaboration among a network of organizations and community-based groups. Almost all of OBCIEP's 36 Coalition partners are provincial or regional groups that sponsor their own web sites. The purpose of the project was to create a private virtual community for those Coalition and corresponding members to share information and assist in the creation of regional or local web sites where none currently exist.

The OBCIEP worked with co-sponsors the Canadian Cancer Society - Ontario Division and Willow, Breast Cancer Support and Resource Services, the Sudbury Regional Breast Health Coalition, and the Thunder Bay Breast Health Coalition. The project had three main components—the creation of two regional web sites for Northeastern and Northwestern Ontario and the development of a functioning "virtual community" for breast cancer information and support groups in Ontario. The Sudbury Regional Breast Health Coalition conducted a pilot project in 2002 through the creation of a regional web site for Northeastern Ontario and in 2003 the Thunder Bay Regional Breast Health Coalition developed a site for Northwestern Ontario. The local working groups in both centres assumed responsibility for the development of the sites, forming partnerships to sustain the project beyond the development stage, and conducted focus groups within their regions to determine the needs of the regional populations which included French speaking populations, First Nations groups and seniors. At the same time the OBCIEP web site, under review since 2001, was revised to include a virtual community component, a "private space" where all Coalition and corresponding members could network, post documents, and share information about new and ongoing projects. Groups who already sponsored their own web sites were encouraged to participate in the new virtual community and groups without their own web sites were invited to create web sites or contribute information to be posted on the OBCIEP web site.

The Sudbury Regional Breast Health Coalition web site at www.breastnorth.info was launched in February 2003. The OBCIEP www.obciep.on.ca was live in May 2003. The Thunder Bay Breast Health Coalition site at www.breasthealthnw.ca was formally launched in October 2003. A training template for users and a template for organizations considering creating their own sites were created. Publication policies were developed and shared among the groups hosting the sites and all project partners.

The following report describes the methods, challenges, lessons learned and achievements of the working groups to the web site developments.

IMPLEMENTING A VIRTUAL COMMUNITY FOR BREAST CANCER INFORMATION AND SUPPORT IN ONTARIO

Introduction

In 2002 it is estimated that 20,700 women in Canada were diagnosed with breast cancer and 5,400 will die of their disease (NCIC, 2002). When breast cancer strikes, its impact is felt in many ways: physically, emotionally, socially, psychologically, and spiritually. To make informed decisions about breast cancer women and their family members need access to the right information presented in a user-friendly fashion at the time it is needed, regardless of where one lives.

During the past several years in Canada many breast cancer groups have developed for the purpose of sharing information and providing support for breast cancer survivors. More recently they have begun to interact for the purpose of sharing resources and enhancing access for their respective members. By working together, these groups strive to avoid duplication, make the best use of scarce resources and better serve the needs of the women in their jurisdictions.

The advent of Internet-based tools and computer technology affords the convenience, quality, and immediate access to information and facilitates communication and information exchange among support groups. (*Virtual Community Feasibility Project: Building Capacity for Tomorrow*, Final Report, OBCIEP, May, 2000). A virtual community for breast cancer information and support makes use of web-based technology and various tools such as websites, bulletin and resource boards, hyperlinks to other sites, e-mail exchange, chat rooms, and document libraries to enhance the collaboration among a network of organizations and groups with a stake in the provision of breast cancer information and support. The vision of the breast cancer virtual community includes public sites accessible by anyone online hosted by various network member group organizations. These public sites are often hyperlinked to each other and are the responsibility of the owner group. The "private space" proposed for these sites would be password protected and is where the business of the network would be conducted. Fundamental to the success of this type of model is the participation by regional and local groups at the provincial level.

Purpose of Project

The Ontario Breast Cancer Information Exchange Partnership (OBCIEP), the applicant for CCB funding, is a coalition of organizations who have a stake in the dissemination about breast cancer proposed a model for a breast cancer virtual community (May, 2000). The regional breast cancer network, the Sudbury Regional Breast Cancer Coalition, based in Sudbury, Ontario recently identified a need in its local and regional area to provide a source of information about breast cancer support and information services to a population often isolated across a wide geographic area. The Sudbury Coalition, which has representation from seven local support, health care, and information groups, suggested the project described in this proposal. Northeastern Ontario currently does not have a website listing all the resources available on breast health/breast cancer and it is recognized that more and more people are searching the web to have access to this type of information. Strategies must be developed to reach the populations that are isolated from the larger centres or who do not have access to computers in their homes and/or require training to learn how to access services already available on the Internet. The Canadian Cancer Society and Willow Breast Cancer Support and Resource Services are also partners in this project.

The Sudbury web site was developed in partnership with all the agencies involved in providing breast information/services. Once the site was established for Sudbury with specific places identified where people can receive training on how to access the information, linkages were to be developed with other communities in the Northeast creating a virtual community for information on breast health/breast cancer support. It was intended that website development process would become a model to be applied with

other regions in the province that will require funding as outlined in the project proposal for 2002-03. Subsequently the Thunder Bay Breast Health Coalition agreed to participate in Phase II of the project to create a regional breast health web site for Northwestern Ontario. The Northwest faces similar issues—a sparse population isolated over a wide area in need of timely information on treatment and support for breast cancer. It is also home to a large Aboriginal population whose information needs are frequently not well met by modern western methods.

Sponsoring Organizations

The sponsor for this project is the Ontario Breast Cancer Information Exchange Partnership. The specific partners for the project are the Northeastern Ontario Regional Cancer Centre, the Thunder Bay Breast Health Coalition, the Canadian Cancer Society, and Willow Breast Cancer Support and Resource Services.

Ontario Breast Cancer Information Exchange Partnership

The Ontario Breast Cancer Information Exchange Partnership (OBCIEP) is a coalition of organizations who have a stake in the dissemination of information about breast cancer. The coalition emerged from the Ontario Breast Cancer Information Exchange Project, originally established in 1993.

During the initial years of the information exchange project in Ontario, the OBCIEP responded to the specific needs of Ontarians by facilitating access to state-of-the-art, user-friendly information about breast cancer and serving as a catalyst for co-operative activity regarding the exchange of information about breast cancer. Representatives of 30 stakeholder organizations from across the province with input from their own networks guided the initiative in the areas where Ontario's breast cancer community lacked a concerted, organized effort. These areas included dialoguing with organizations involved in providing breast cancer information, sharing information about existing resources, responding to the needs of women and health care providers, and identifying and filling information gaps. As gaps were identified, various member organizations are encouraged to take leadership in filling those gaps.

The primary role of the OBCIEP is to assist organizations, involved in the dissemination of information, to respond to the information needs of their clients. We accomplish this by sharing information about breast cancer resources through our newsletter, web site and various communication tools used by our member organizations. In collaboration with others, we also develop information resources for women, their families, and health care professionals to fill identified gaps. In addition, our activities involve the evaluation of existing dissemination strategies to ensure that people can easily access quality, state-of-the-art information when they need it.

OBCIEP is committed to ensuring information about breast cancer is available to all people in Ontario. The strategic directions for the OBCIEP are set by a Coalition of Stakeholder organizations consisting of 37 cancer and breast cancer groups from across Ontario. Of all the organizations involved, over half are grassroots and breast cancer survivor-directed groups. By providing a neutral forum for networking and information exchange at the provincial level, the OBCIEP fosters co-operative problem solving and co-ordinated action concerning issues related to breast cancer information dissemination. Whatever the activity, the fundamental philosophy of the OBCIEP remains in the forefront—that the development and dissemination of information about breast cancer be guided by those directly affected by the disease.

In 1999, the OBCIEP provided leadership for the development of a strategic or action plan for Ontario regarding breast cancer information and support entitled, "The 1999 Ontario Action Plan for Breast Cancer Information and Support". This report was produced following a Think Tank Conference held in April 1999, with funding from Health Canada. The Think Tank was attended by 120 representatives of

breast cancer organizations and breast cancer survivors from across Ontario. The new project proposed in this document is based directly on the needs regarding breast cancer information and support that were identified at the Think Tank Conference. (e.g., the need for a strong regional network to deal with current gaps in information and supportive and community action plans)

In 1999 the OBCIEP began a feasibility study on the development of a national virtual community for breast cancer information and support. The Virtual Community project, that included a workshop held in Toronto in March 2000, was mounted to explore the feasibility of using Internet based tools to foster work in the dissemination of breast cancer information and the provision of support for breast cancer survivors. This project, conceived as the first step toward establishing a virtual community, was funded through the Population Health Fund of Health Canada as part of the Phase II Canadian Breast Cancer Initiative focussing on Community Capacity Building. As part of the research completed prior to the full day workshop, surveys were conducted to determine the goals for a virtual community, Internet access and use, and perspectives on establishing virtual communities. The report outlined a proposed model for a virtual community that is to be applied in this project at a regional level. The OBCIEP is in a unique position to be the sponsoring organization for this new initiative in Ontario. We have developed a network of relationships with a reputation for effective collaboration and have initiated research in the area of Internet-based technology and its application to an information and support network.

Canadian Cancer Society - Ontario Division

The Canadian Cancer Society (CCS) is a national community based organization of volunteers, whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. In partnership with the National Cancer Institute of Canada, it achieves its mission through research, education, patient services and advocacy for health public policy. These efforts are supported by the network of volunteers and staff and the fund-raising efforts in communities across Canada.

The Canadian Cancer Society is a leader in the fight against breast cancer. It is a founding and funding partner of the Canadian Breast Cancer Research Initiative, now the Canadian Breast Cancer Research Partnership (CBCRP). The CBCRP, formed in 1993, is now the primary funder of breast cancer research in Canada.

The CCS is a leader in providing current, reliable information about all aspects of breast health and breast cancer. Information about breast cancer is easily obtained by calling the Canadian Cancer Society's Cancer Information Specialists or by contacting local CCS offices. As well, CCS and its Cancer Information Specialists direct women to services in their local communities that will help them cope with their breast cancer. CCS also provides emotional support to women with breast cancer through programs such Reach to Recovery and Cancer Connection. This latter program matches breast cancer survivors with newly diagnosed women to offer support via telephone.

The Society is a partner organization in the Canadian Breast Cancer Initiative and, as such, participates with other breast cancer organizations to ensure that the needs of women with breast cancer are met in the best ways possible. CCS also strives to improve the quality of life of those affected by cancer, reduce tobacco use and increase support for research. This is achieved through vigorous revenue development, sustained volunteer development and effective planning, evaluation and resource management. The Ontario Division of the CCS has played a key role in the evolution of the OBCIEP, participating in the Advisory Panel of Stakeholders and the development of many of the information tools over the past several years. Most recently, the Ontario Division made its commitment to the work of the OBCIEP very clear by funding the full-time salary for the position of the OBCIEP Co-ordinator. Regional offices of the CCS also provide support to the Northeastern and Northwestern Ontario Coalitions.

Willow, Breast Cancer Support and Resource Services

Willow, Breast Cancer Support and Resource Services is a survivor-directed, charitable organization that provides information and emotional support to individuals diagnosed with breast cancer, their families, and caregivers, as well as to health care professionals dealing with the psychosocial needs of their patients. Founded in 1994 by a group of survivors, Willow, Breast Cancer Support and Resource Services is committed to ensuring the accessibility to information and support to all communities including geographic, ethno-cultural, linguistic and disabled, through a Canada-wide toll free line, a comprehensive resource service, an interactive web site, and training workshops.

Regional Partners

Northeastern Ontario Regional Cancer Centre and the Sudbury Regional Breast Health Coalition

The Northeastern Ontario Regional Cancer Centre (NEORCC) opened in 1990 and its mission is to control cancer and its impact on the people of Northeastern Ontario, through partnerships with patients, their families and other individuals and agencies. Currently the Centre treats over 2,100 new cancer patients each year. Due to the size of its catchment area the NEORCC has developed several innovative programs with its community healthcare partners and is recognized provincially as a leader in providing cancer care “closer to home”. Its partners include the Sudbury Palliative Care Association, the Ontario Breast Screening Program (OBSP), Sudbury Regional Hospital, the Canadian Cancer Society, and the Sudbury Health Library Information Network.

NEORCC’s partner on this project is the Sudbury Regional Breast Health Coalition that includes representation from the NEORCC, the OBSP, the Canadian Cancer Society, the Sudbury Regional Breast Health Program, the Circle of Strength Sudbury Breast Cancer Support Group and the Sudbury and District Health Unit. The group was in a unique position to host the pilot as there is a network of local and regional health care and support organizations already working together and grappling with the challenges of reaching remote communities over long distances.

Thunder Bay Breast Health Coalition

Thunder Bay Breast Health Coalition was founded in January 1993, and is comprised of organizations in the Thunder Bay area that are interested in breast health. Its goal is to increase breast health awareness among all women and spread information on breast abnormalities to all health care providers. Representatives from the Thunder Bay & District Breast Cancer Support Group, Breast C.A.R.E.S (Cancer Assessment and Resource Education Services), the Thunder Bay District Health Unit, the Northwestern Ontario Regional Cancer Centre (NWORCC), the Canadian Cancer Society - Ontario Division, Northwestern Region, and the Ontario Breast Screening Program, Northwestern Unit participate. The Coalition is described in more detail in Section II of this report.

Partner Roles

The project partners were involved in all stages of the project design, planning and implementation. The OBCIEP worked with the Sudbury Regional Breast Health Coalition (SRBHC), the Thunder Bay Breast Health Coalition (the Coalition), the Canadian Cancer Society - Ontario Division and Willow Breast Cancer Support and Resource Services. The latter two organizations have networks of contacts throughout Ontario at both the regional and local levels and participated in the projects.

Project Origins

The Virtual Community Feasibility Study (OBCIEP, 2000) was undertaken to establish the feasibility of using a virtual community approach to foster the work of disseminating information about breast cancer and providing support to survivors. Based on the information gathered, it is clear that a virtual community approach has the potential to enhance collaboration between and among stakeholder organizations in

breast cancer. Two fundamental considerations were identified in moving forward to establish a virtual community. One was technology—currently the technology exists and the creation of a model as proposed in this document is fairly easy and is not extremely costly. The second consideration is the "buy-in" from breast cancer organizations and groups.

TABLE 1: Issues Perceived in Becoming Part of a Virtual Community, Virtual Community Feasibility Project, OBCIEP, May 2000

Type of Group	Percentage of Responses (respondents could answer more than one option)						
	Access to Internet	Hardware Costs	Software Costs	Set-Up Issues	Training Costs	Maintenance Costs	Security/Privacy
Professionals 11	27	36	36	27	27	18	18
Support 65	66	54	54	66	63	57	38
CCS Units 28	46	32	36	39	36	61	46
Hospitals/ Programs 24	50	38	46	50	38	46	33
Cancer Centres 13	27	33	27	47	53	60	33
Networks/ Coalitions 13	31	38	54	38	54	46	46
Other 17	12	12	24	18	35	53	41
Total = 173	47	41	45	49	49	52	36

Based on these issues it was important to begin the implementation of a province-wide virtual community in a focussed (e.g. regionally specific) manner. By working with an existing regional network of breast cancer agencies, organizations, and support groups, the OBCIEP would be able to learn about specific barriers to the success of a virtual community and identify (and implement) creative solutions with the regional partners. The barriers identified in the 2000 Feasibility Project were used as the basis for early discussion and planning the implementation with the group in Sudbury. The pilot project included opportunities for the following activities to be undertaken collaboratively with regional stakeholders:

- ◆ assessment of barriers/needs of potential users (members of the virtual community)
- ◆ exploration of opportunities to overcome barriers
- ◆ assessment of education and training needs
- ◆ design and offering of education and training sessions.

Emerging from planning discussions around the OBCIEP Community Conversation Gatherings (*Promoting Regional/Local Capacity for Breast Cancer Information Dissemination and Provision of Support in Ontario*, Community Capacity Building Project 2000), the Sudbury Regional Breast Health Coalition identified a need to provide breast cancer information and services to a population isolated across a wide geographical area. The Coalition proposed a pilot project to develop and implement a virtual community model for Northeastern Ontario. This became Phase I of the project. A similar project was undertaken by the Thunder Bay Breast Health Coalition for Northwestern Ontario and became part of Phase II with the development of the OBCIEP provincial virtual community. The projects are described below.

PHASE I - THE SUDBURY PILOT PROJECT, NORTHEASTERN ONTARIO BREAST HEALTH/CANCER WEB SITE

The Pilot

The Sudbury Regional Breast Health Coalition began the Northeastern Ontario Breast Health/Cancer web site project in the fall of 2001. A report was produced in June 2003 regarding this web site project for the Sudbury Regional Breast Health Coalition to share with their regional partners. The report includes a full description of the work plan, activities, and outcomes. A full copy of this report appears in **Section II**. A brief project description, key findings and recommendations are provided below.

Participants

The Sudbury Regional Breast Health Coalition working group included:

Claire McChesney	Chair, Program Leader Prevention/Education/Quality, NEORCC
Sharon Bowes	Ontario Breast Screening Program - Sudbury, Health Promotion
Nancy Hammell	Willow Breast Cancer Support and Resource Services
Carolyn Jackson	Ontario Breast Screening Program - Sudbury Hub Site
Anita Lovin	Circle of Strength, Sudbury Breast Cancer Support Group
Maureen MacMillan	Sudbury & District Health Unit, Public Health Nurse
Carole Mayer	Sudbury Regional Breast Health Program, NEORCC, Program Coordinator of Clinical Services
Nicole McGaughey-Paparo	Canadian Cancer Society - Ontario Division, Sudbury Unit
Carreen O'Connor	NEORCC
Jane Pitblado	Circle of Strength, Sudbury Breast Cancer Support Group
Jami vanHaften	Cancer Care Ontario/NEORCC, Librarian
Chantal Rancourt	Project Coordinator
David Evans	Web Developer
Irene Nicoll	OBCIEP Coordinator
Rachelle Foster	Secretary
Nicole Cummings	Secretary
Denise Gauthier-Frolick	Consultant Focus Groups, NEORCC
Sandra Rinaldo	Sudbury & District Health Unit, Logo Design
Cancer Care Ontario	Translation Services
NEORCC	Communications and Promotion assistance

A provincial project group was also established to review the local group's progress and offer feedback on the test web site. This group was:

Margaret Fitch*	Director, OBCIEP
Beth Easton*	Canadian Breast Cancer Foundation - Ontario Chapter
Raylene Godel*	Breast Cancer Survivor
Eleanor Nielsen*	Breast Cancer Survivor
Patricia Payne*	Canadian Cancer Society - Ontario Division
Dallas Petroff*	Willow Breast Cancer Support and Resource Services
Representative ~/~	Bayview Support Network, Toronto, Connecting Rainbows, Markham
Jan Lewkin~	Thunder Bay Breast Health Coalition, Thunder Bay
Representative≈	Breast Cancer Research and Education Foundation, St. Catharines
Representative ≈	Breast Cancer Action Kingston, Kingston

- *members of OBCIEP Operations Group, based in Toronto
- ~ survivor group does not have web site
- ≈ survivor group does have web site

In addition the URLs or Internet addresses of the test sites for both the Sudbury Pilot Project and the OBCIEP web site were distributed to all 37 OBCIEP Coalition members, over 60 support groups and other breast cancer organizations to solicit general comments and reviews.

Project Description

The project began in the March 2002 when a project coordinator was hired to develop the web site and manage other project activities.

Arrangements were confirmed with Northeastern Ontario Regional Cancer Centre (NEORCC) that the Cancer Center would host the web site and remain responsible for technical maintenance and repair. Site content was the sole responsibility of the Sudbury Regional Breast Health Coalition. The challenge identified for the developer was to produce an extremely user-friendly software mechanism for volunteer Coalition members to update and maintain site content.

The breast cancer information guide produced by Circle of Strength, the Sudbury & District Breast Cancer Support Group, was the basis of the information on breast cancer, support services and community services information first transferred to the web site. Coalition members were initially faced with the challenge of presenting the written booklet information in appropriate web format, and eventually to adapting and reorganizing increasing amounts of information within the determined framework. All information was to be available in both French and English. Additions to and revisions to information on the site took several months.

Concurrently focus groups were conducted in three communities outside of Sudbury in Chapleau (a French-speaking community), Elliot Lake (seniors' community) and at the Wikwemikong First Nations Reserve. Results from the focus groups in Chapleau and Elliot Lake indicated that most people had computer access at home or through family members or knew of several locations nearby, (i.e., such as the local library) where members of the public had access to the Internet. Almost all participants, with the exception of those at Wikwemikong, had had first-hand experience browsing the Internet. Participants specified the type of information they wanted on the site and suggested ways to promote the site to their community. The challenges at Wikwemikong were more demanding due to the economic pressures on the reserve. The health care workers who attended the focus group were pleased that the site would highlight regional resources and services.

In December, 2002, the test site was evaluated for both ease of use and content by health care workers and cancer patients at NEORCC. Comments were summarized and prioritized by the working group to be addressed prior to or after the formal launch date. A training template was developed for people not familiar with computers as well as a template for other regional groups to use in the creation and maintenance of a breast cancer information site. A privacy statement, an advertising policy and a disclaimer were developed and posted on the site to comply with the "HON code" developed by the Health on the Net Foundation's main principles. A public relations and communications expert at the NEORCC assisted in the development of a promotion plan for the web site. Translation services at NEORCC translated all site content into French.

The formal launch was held in Sudbury at NEORCC on February 26, 2002. Dr. Margaret Fitch, Director of OBCIEP and Janice Skot, Vice President Regional Cancer Program and Clinical Services NEORCC participated at the ceremony together with members of the working group. Press coverage of the launch

included newspaper articles, radio interviews in English and French, and coverage on the local news station.

Key Findings

Initially the work plan scheduled the web site for completion within 12 months. This became impossible when hiring problems delayed the recruitment of a project coordinator. Additionally, and unexpectedly, two key committee members retired from work and the working group. A number of findings were identified by the completion of the project:

- combining web development and project coordination was an inefficient combination as key work was required on the site at the same time as project management of personnel and information on the site became paramount;
- adapting existing information resources to web format was challenging—information developed specifically for the site separately was easier to organize and present than pre-existing information resources;
- while the Coalition accepted the responsibility of maintaining site content, there was a lengthy learning curve for members to feel comfortable with the process;
- many excellent breast cancer information resources already exist online and efforts were made to link to rather than re-create information currently available;
- the focus groups highlighted participants' keen interest in "mapping" a person's journey through treatment—they requested that all pertinent details for people coming to Sudbury for treatment be explained such as driving and parking directions, what NEORCC looked like, where it was, where volunteers were located who could help, length of stay, where family members could stay, etc.;
- increasing access to online information sources by providing computers to breast care centres proved difficult as access to and payment for Internet services and concerns about system security prevented some centres from participating; and,
- innovative solutions are necessary for those living on First Nations reserves where opportunities to access online information sources are limited.

Outcomes

The Northeastern Ontario breast health/cancer web site project produced a number of significant results and tools that can be used and/or adapted for use by other community groups:

- completion of the bilingual web site at www.breastnorth.info;
- a summary of key considerations for community groups developing a web site that addresses purpose, participants, funding, content, sustainability, promotion and evaluation considerations;
- evaluation tools to assess target audience information needs;
- evaluation tools to assess the web site;
- detailed communication plans to promote the site and the formal launch celebration;
- sample media advisories, releases, and invitations for special event launches;
- policies on site content and technical maintenance and updates which could be adapted by other groups;
- disclaimer, authorship, privacy and advertising policy statements which could be adapted by other groups; and,
- a one-page teaching guide for people unfamiliar with computers to access and search the web site.

Another welcome outcome of the project is a revitalization of the Sudbury Regional Breast Health Coalition. The Sudbury group is a coalition of health care and education representatives from various groups in the Sudbury area who met periodically to plan and conduct individual breast health/cancer related events. The web site working group was a "task force" of the Coalition and assumed chief

responsibility for the site. Throughout the project a number of other issues arose about addressing needs of breast cancer survivors in the Sudbury district and Northeast Ontario. At the conclusion of the web site project the Coalition discussed plans for a visioning day to examine interest in formalizing the Coalition as a structured ongoing body to address community issues around breast cancer in education, information and support, advocacy, and fund raising. Plans are also being discussed for an education day in 2004 on breast health related topics.

The Sudbury Regional Breast Health Coalition followed the development of the Northwestern Ontario breast cancer information web site and reviewed the BSE sites. The Thunder Bay Breast Cancer Coalition's work in turn fostered the Sudbury Coalition as the Thunder Bay web site policies and Task Force Terms of Reference were reviewed for adoption by the Sudbury Coalition. In the fall of 2003 the Sudbury Coalition, working in partnership with information technology students at some local high schools, was planning to add graphics, photographs, and portions of teaching and support videos to the Northeastern Ontario web site. The desire to create a more visually pleasing and interactive tool was inspired by the style and format of *BreastHealthNW*. Finally, the Sudbury Coalition has invited an oncologist, a surgeon, and a family physician to participate on an editorial board for the web site that will include members of the Coalition and breast cancer survivors.

www.breastnorth.info



PHASE II - NORTHWESTERN ONTARIO BREAST HEALTH/CANCER WEB SITE

Background

In the original OBCIEP project proposal Phase II was described as the province-wide implementation of the virtual community model. Building on the Sudbury pilot project, the project sponsors sought to develop new electronic information sources where none existed. In the fall of 2002 the Thunder Bay Breast Health Coalition was completing a web site on breast self-examination (BSE) through a grant by the Canadian Breast Cancer Foundation - Ontario Chapter. At the OBCIEP Coalition of Stakeholders meeting in September 2002 the Thunder Bay representative was approached about the possibility of developing a breast health/cancer information web site for Northwestern Ontario. The Thunder Bay Breast Cancer Coalition the group agreed to participate in the project and in December 2002 an aggressive timetable of activity was developed for completion of a web site in six months (Appendix I).

The OBCIEP web site was also nearing completion and OBCIEP committed to working with five breast cancer information and support groups to launch the virtual community model. This work would promote the continued use of the electronic network and assist those groups, not currently online, to develop a web page. The groups targeted for participation in the virtual community model were located in Ottawa, Kingston, Sudbury, Burlington, St. Catharines, and Thunder Bay. All groups at these locations sponsor web sites, some with a more regional rather than local focus.

Thunder Bay Breast Health Coalition

Thunder Bay Breast Health Coalition (the Coalition) was founded in January 1993 and consists of organizations in the Thunder Bay that are interested in breast health. Its goal is to increase breast health awareness among women and distribute information on breast abnormalities to health care providers.

Coalition members include but are not limited to the following organizations:

Thunder Bay & District Breast Cancer Support Group

This group has functioned as a support network with a membership of 90 women during the past ten years. It sponsors monthly meetings and produces a monthly newsletter. The group is allied with provincial and national breast cancer initiatives and research projects.

Breast Cancer Assessment and Resource Education Services (CARES)

Breast CARES is a program for women of any age who have a breast health problem or concern, whether or not they have a family physician. Breast CARES is a pilot program of the Division of Preventive Oncology, a partnership between the Thunder Bay District Health Unit and the Northwestern Ontario Regional Cancer Centre.

Thunder Bay District Health Unit

Thunder Bay District Health Unit is a non-profit agency funded by the municipal and provincial governments with offices in Thunder Bay, Geraldton, Manitouwadge, Marathon, Nipigon and Schreiber. The Thunder Bay District Health Unit is mandated to educate women about the early detection of breast cancer.

NorWest Community Health Centres

The NorWest Community Health Centres provide health care and health promotion programs in Armstrong, Longlac, and the Ogden-East End neighbourhood in Thunder Bay. As part of a network of 56 Community Health Centres, they have been providing services for more than 10 years.

Northwestern Ontario Regional Cancer Centre (NWORCC)

The Northwestern Ontario Regional Cancer Centre (NWORCC) offers treatment, information and support to women with breast cancer in Northwestern Ontario. There is a library of cancer resources and the Department of Supportive Care Services offers both individual and group counselling for patients and their family members. Clinical trials are underway on the prevention and treatment of breast cancer.

Northwestern Ontario Breast Screening Program (OBSP)

Northwestern OBSP has a mobile van that offers clinical breast examinations and mammography to women age 50 and over. The NWORCC and the Ontario Breast Screening Program oversee this free service that includes the region from the Manitoba border east to Chapleau and Wawa.

Northwestern Unit of the Canadian Cancer Society

The Northwestern Ontario Unit of the Canadian Cancer Society - Ontario Division provides service to Northwestern Ontario serving all communities from the Manitoba border through White River. The regional office is located in Thunder Bay. Services include support for people living with cancer, family members and friends, comprehensive and credible information on cancer, risk reduction and treatment, and provincial and regional fund raising for research and support for those affected by cancer.

Participants

A local project group was established that included breast cancer survivors, health care professionals, local representation from the project partners, CCS-Ontario Division and Willow. The original local project group was:

Thunder Bay Local Project Management Group

Jan Lewkin	Breast Cancer Assessment Resource and Education Services (Breast CARES)
Kiri Butter	Canadian Cancer Society - Northwestern Ontario Region
Eileen Dias	Thunder Bay District Health Unit
Anita Jean	NorWest Community Health Centres
Bonnie Lindberg	Northwestern Ontario Breast Screening Program
Barb Midgely	Thunder Bay & District Breast Cancer Support Group
Alison McMullen	Northwestern Ontario Regional Cancer Centre
Cindy Sinnott	Northwestern Ontario Regional Cancer Centre
Karen Weselak	Thunder Bay & District Breast Cancer Support Group
Heather Woodbeck	Northwestern Ontario Regional Cancer Centre, Cancer Care Ontario
Rhonda Usenik	Thunder Bay District Health Unit
Kathy Thompson	Project Coordinator, Thunder Bay
Irene Nicoll	OBCIEP Coordinator, Toronto

Provincial Review Group

Representative *	Bayview Support Network, Toronto
Carol Burnham-Cook*	Willow Breast Cancer Support and Resource Services, Toronto
Representative	Guelph & Wellington Breast Cancer Support Group, Guelph
Representative	Guelph & Wellington Breast Cancer Support Group, Guelph
Representative	START, (Surviving Together and Recovering Together), Kenora
Representative	START, Kenora

Representative	Breast Cancer Research and Education Fund, St. Catharines
Representative *	Breast Cancer Action Kingston
Representative	Milton Breast Cancer Support Group

*representatives of groups that host web sites

OBCIEP Operations Group, Toronto

Margaret Fitch, Director	Director, OBCIEP
Beth Easton	Canadian Breast Cancer Foundation - Ontario Chapter
Raylene Godel	Breast Cancer Survivor
Eleanor Nielsen	Breast Cancer Survivor
Patricia Payne	Canadian Cancer Society - Ontario Division
Dallas Petroff	Willow Breast Cancer Support and Resource Services

Project Description

Progress on Phase II is described below in accordance with the activities outlined in the project work plan and objectives. Work began in January 2003.

Objective 1

Develop and implement a regional web site concerning resources for breast cancer information and support for Northwestern Ontario

The breast health web site www.breastnorthnw.ca was developed for Northwestern Ontario.

Activities

1. *Establish a shared vision of a virtual community in breast cancer information and support and find project sponsor to host site in Thunder Bay.*

The TBBHC adopted the *Vision for Virtual Community for Breast Cancer Information and Support* document developed by the OBCIEP (Appendix II).

2. *Develop preliminary specifications and navigation bar for web site.*

Kathy Thompson, Project Coordinator worked with Norlink, a web developer and service provider the Coalition had worked with in developing BSE web site. A preliminary menu was presented in February. By June a full menu had been revised and updated in response to the needs reviewed at the focus groups. The name of the site, *Breast Health Northwest*, was chosen and the URL for the site selected and registered as www.breasthealthnw.ca.

3. *Review/adapt new and existing information resources for inclusion on the site.*

The Coalition's information resources are principally two pamphlets, 1) "How to Check Your Own Breasts for Health" is the basis of the breast self-examination web site; and 2) "If You Have a Breast Concern" includes brief information about breast abnormalities and contact information for a variety of breast screening, information and support organizations in the Thunder Bay region. The contact information was expanded for the Northwest region of Ontario, the content updated and posted online at *BreastHealth Northwest*.

Linking to either or both the NWORCC inventory of services and the Cancer Information Service's directory of community services was explored. The possibility of creating special "breast health/cancer" section on the NWORCC web site was investigated but at the time of this project NWORCC was planning a major redesign of its web site. The Cancer Centre is also moving to a new location. As the NWORCC web site redesign was pending but not scheduled, the Coalition agreed to delay the creation a link to the NWORCC patient/visitor information web page. Information on "Your Visit to the Cancer Centre" adapted from the NWORCC publication *Patient Journey* is presented with permission on *BreastHealth Northwest*. This information will be revised when the Cancer Centre relocates in early 2004.

4. *Design/draft web page with links to other breast cancer information resources.*

A test site and initial design of a home page were developed in February. Information was added gradually over time so the site reviewers could browse the site and evaluate the navigation tools and content headings as the site developed. Project Coordinator K. Thompson assumed responsibility for adding content, links and other information to the test site. Coalition members and community stakeholders identified topics and areas of interest during the community consultation process. Information about community resources was gathered from key informants in communities across the Northwest. The Coalition consciously made the decision not to recreate information already available on other credible sites. Instead, the Coalition chose to develop the site as a portal to other sites where information is kept up-to-date and accurately reflects changes in care, treatment, research, and prevention/early detection.

5. *Develop policies, procedures, security, access, etc.*

The working group relied heavily on the work completed during Phase I by the Sudbury Regional Breast Health Coalition, particularly for previously documented work on policies, procedures and focus group preparation. OBCIEP's working draft on publication policies and procedures, and the "BreastNorth.info" disclaimer, authorship, and advertising statements were adopted in principle at the early stages of the project and reviewed in detail as the web site was constructed. The BreastHealthNW web policies were approved by the Thunder Bay Breast Cancer Coalition in September 2003 (see Appendix III).

6. *Address identified barriers (see Table I, page 9) to implement the virtual community concept in a diverse geographic area*

The Coalition decided that this activity was best served through focus group discussions that would serve also Objective 2: strengthening ties and linkages and developing new linkages between the Coalition and other Northwestern communities outside of Thunder Bay.

Regional meetings to obtain feedback from communities on information needs, web site specifications, and other Coalition activities were planned for early April. The SARS outbreak in Toronto at that time initiated a ban on health workers meeting for several weeks and the original focus group schedule was abandoned. A new travel schedule was approved and followed in May. K. Thompson, Project Coordinator attended all sessions. Coalition members J. Lewkin, B. Lindberg, and R. Usenik attended the first four meetings and B. Lindberg attended the final five.

Northwestern Ontario Focus Group Schedule

<u>Date</u>	<u>Location</u>
May 1	Nipigon/Red Rock (lunch meeting) Terrace Bay/Schreiber (evening)
May 5	Marathon (lunch meeting) Manitouwadge (supper meeting)
May 12	Atikokan (lunch meeting)
May 14	Dryden (lunch meeting, health care providers) Dryden (evening meeting, consumers, survivors)
May 15	Kenora (lunch meeting, health care providers) Kenora (evening meeting)

K. Thompson contacted key health care professionals and breast cancer support group representatives in the seven communities. These contacts were vital links within the communities and through their efforts the focus groups were promoted and community representatives were invited to attend. The Coalition also sent individual invitations. Participants at the sessions included breast cancer survivors and various members of the health care team as follows:

Location and Number Attending	Participant Designation
Nipigon/Red Rock (6)	Survivors, nurse practitioner, Director of Nursing, women's health advocate
Terrace Bay/Schreiber (3)	Survivor, Canadian Cancer Society representatives
Marathon (4)	Survivors, personal care worker, Pic Mobert First Nation
Manitouwadge (13)	Survivors, health unit representatives, x-ray technologist, physician, Canadian Cancer Society volunteers, consumers, nurses, mental health worker
Atikokan (10)	Survivors, mental health worker, First Nation social workers, Canadian Cancer Society
Dryden (24)	Survivors, Director of Nursing, health unit staff, nursing staff, radiology department staff, chemotherapy nurses, Canadian Cancer Society representatives, consumers
Kenora (13)	Survivors, nursing staff, chemotherapy nurses, operating room nurses, health unit and Canadian Cancer Society representatives

Summary of Focus Group Surveys and Discussions

Focus group invitations, letter of consent, and questions appear in Appendix IV. Detailed summaries of the survey responses and discussion notes from the nine focus group sessions appear in Appendix V and Appendix VI.

Over 60% of the survey respondents were over the age of 50 and sixty-six percent reported completing some or graduating from college or university, reflecting the participation of a number of nurses and other health care providers. English was reported as the first language for over 90% of the respondents. Over 70% indicated they have had experienced using a computer and browsing the Internet, most by using home computers with regular (not high speed) dial-up connections. Of those who browsed the Internet, 73% consider their skills intermediate or advanced.

Respondents were asked during the group discussions about information that should be included on the web site, barriers to accessing the information, how to promote the web site in the Northwest, the

web site's audience, and if there was interest in the specific community about creating a support group and/or developing a web page for the site. Responses are summarized below:

Audience for Site

There was general consensus that the main audience for the web site would be people and their families dealing with a breast concern though it could reach a larger group depending on promotion.

Information to Include on the Site

Both survivors and health providers at the sessions voiced a need for detailed information for patients who have to travel away from home for treatment. Similar to the findings in the Sudbury region, participants wanted very specific information available online about driving and parking directions, accommodation, contacts/volunteers at the cancer centre, etc. during their treatment. A significant number of patients in Northwestern Ontario travel to Winnipeg for treatment so information on travel to Winnipeg was also requested. Survivors requested tips for travelling also be included.

Medical and technical information was requested on surgery, medical treatment options, clinical trials, lumpectomy, mastectomy, lymphedema, reconstruction, and drug side effects. The Coalition determined that accurate, updated information of this nature is available on other web sites such as the Canadian Cancer Society, Health Canada, and Canadian Health Network. Thus where possible, links were provided to these sites. Information on services available to women in the Northwest who are dealing with a diagnosis, from emotional support to practical needs such as where to obtain wigs and prostheses, was also included.

There were also expressions about the need for emotional and support contacts in outlying areas. While services such as the Canadian Cancer Society's Reach to Recovery program operate in the region, the Northwest has experienced a shortage of volunteers to participate in the program. Participants indicated that information on treatment and on support services should be made available women at the time they are diagnosed, not after treatment has begun. There were requests to present the information in user-friendly, easily understood English and where possible in graphic or other formats more accessible to other cultural groups. Nurses at one session cautioned about linking to or highlighting information from daily newspapers that may contain erroneous information, possible misrepresentations about recent drug studies or other study results that people may find confusing and/or troubling. They also requested that strict content guidelines be observed for information posted to web pages on the site hosted by local support groups.

Barriers to Access

It was noted that most of the Internet access in the Northwest is currently provided through dial-up connections that can be slow and inefficient and connections can be broken. While libraries offer access to the Internet, their hours are limited and some have to charge a fee for the service. Some communities had limited access in community centres, some reported several options for access but free training for seniors and those unfamiliar with computers is limited. Participants felt that seniors would not access information from the Internet directly. While this is recognized as a barrier, it is also believed that information from the Internet is obtained indirectly from health care providers, family members, neighbours, the Canadian Cancer Society unit offices, and other community centres.

Local Community Page

Most communities felt they could not host a web page but interest was expressed in Thunder Bay, Dryden, and Kenora. In Manitowadge, a new breast cancer support group may start and tentatively agreed to consider the option. Other participants indicated it was an interesting idea but could not identify volunteers to maintain the page.

Promotion of the Site

A number of venues to promote the site were suggested. These included the usual regional media such as newspapers, radio, and local television. Participants recommended use of posters in medical centres, mailbox inserts, ad bags and advertising at other local health conferences and sporting events such as curling bonspiels.

Overall, the response to the project was very positive and participants felt it merged well with the recent release of the BSE web site that enhanced promotion possibilities for both sites.

7. *Identify activities necessary to sustain the project beyond the pilot stage.*

The NWORCC was not in a position to host the site and the Coalition already had arrangements with Norlink to maintain the BSE site. The Coalition was able to negotiate a five-year contract with the company (to be paid annually) to host the site at a reasonable cost. This arrangement allows the Coalition time to consider longer-term arrangements and to reassess possibilities with the NWORCC when relocation and integration of the Cancer Centre to Thunder Bay Regional Hospital is completed.

8. *Develop, review and evaluate web site with partners, community members, and survivors.*

The Thunder Bay Breast Health Coalition designed and developed the site with web developer contractor Norlink of Thunder Bay. Tab selections and content were added over time and many revisions to the site content took place over the next six months. A detailed web site menu is shown in Appendix VII. An initial link to NWORCC information for visitors is shown in Appendix VIII. Focus testing questions were available (and subsequently revised) on the original test site. A sample appears in Appendix IX. The online survey automatically tabulated and summarized responses.

Only 12 people completed the online focus test questions. Initially the online survey included ratings of each section of the site and questions regarding the software and server options used by the browser. The survey was revised to include fewer questions and system questions were removed, as many browsers do not know the technical systems they are using. The results of the survey and comments are shown in Appendix X. In each of the three major questions on ease of use and readability users ranked the site eight or nine out of 12. Comments received at meetings and in other e-mail messages not included in the online survey have equally been very positive.

The Coalition received permission to use candid photographs of regional breast cancer survivors on the web site masthead. The photographs used in the original design were stock photographs available for public use. The Coalition wanted to personalize the site and received permission from several breast cancer survivors and those working in breast health/cancer fields to include their photographs on the home page over a background map of Northwestern Ontario. All of the women who appear on the current home page are residents of Northwestern Ontario.

Promotion

After the community consultations in the spring, the Coalition's contact with site reviewers was mainly through e-mail contact. In July, at the 5th Annual Thunder Bay Dragon Boat Race Festival, 500 copies of the revised brochure *If You Have a Breast Concern* (that highlights the web addresses for *BreastHealth Northwest* and the new bilingual BSE sites) were made available to participants and the public.

The site was nearing completion in the fall of 2003 and launch plans took advantage of the many events organized for October, Breast Cancer Awareness Month. The Coalition created a media

release on the project (Appendix XI) and invited local, regional, and provincial politicians and those in the medical community to the formal launch. Samples of promotional items and media coverage appear in Appendix XII.

In late September the site was profiled in the OBCIEP newsletter. Over 4,300 copies of the newsletter are distributed in Ontario and 200 copies were provided to the organizers of the fall 2003 Kenora Breast Health Forum.

On October 4, a display about the site was featured as part of the Dryden Breast Cancer Luncheon of Hope. Approximately 100 people were in attendance. Project Coordinator, Kathy Thompson, was one of three guest speakers at the luncheon and she spoke about the BSE web site, and the *BreastHealth Northwest* web site and announced the inclusion of the Dryden mini-site. The theme of the luncheon was Hope. Local media coverage included an article in the Dryden Observer on Wednesday, October 8, 2003.

Twelve hundred (1,200) **Breast Health Online** computer monitor stickers displaying the addresses of the *BreastHealth Northwest*, *BreastSelfExam* and *ExamenDuSein* web sites were placed in kits for participants at the Thunder Bay Canadian Breast Cancer Foundation Run for the Cure on October 5.

A small formal launch ceremony was held on October 7 at the Northwestern Ontario Regional Cancer Centre. Jan Lewkin acted as chair and provided an overview of the Coalition. Millie Gormely, President of the Thunder Bay Branch of the Canadian Cancer Society delivered a message of congratulations from Dr. Margaret Fitch of OBCIEP. Diane Richmond, an aboriginal breast cancer survivor and health care worker from Marathon, spoke about the importance of the web site to women in small northern communities. Kathy Thompson provided an overview of the project and conducted a brief tour of the site. A reporter from the Chronicle Journal and another from Dougall Media (which represents three radio stations, two television stations, one newspaper, and four web sites) were on hand for the launch. Coverage included: an article in the Chronicle Journal, hourly news reporting on CKPR, Hot105, and Rock 94 radio; CBC Radio Thunder Bay, an interview with K. Thompson on CBC Radio (French – Sudbury); coverage on the evening news on CKPR-TV and CHFD-TV as well as their weekly TV News show – Northwest News; and, coverage on the web sites for Chronicle Journal, CKPR, Hot105, Rock94, TBSource, TBTv.

On October 16 a mini-launch was held at the Kenora Breast Health Day, a breast health forum sponsored by the Kenora Keeping Abreast Coalition and the Northwestern Health Unit. The event included displays and lectures and was free to the public. Jan Lewkin spoke about the Breast CARES program, Dr. Vergidis discussed breast cancer. A last minute cancellation of a guest speaker provided a podium launch opportunity when the meeting planners invited Project Coordinator, Kathy Thompson, to speak about BreastHealthNW and the BSE sites. The forum attracted over 200 women from the Kenora area. Over 300 monitor stickers, *If You Have a Breast Concern* pamphlets, and *Every Month is Breast Cancer Month* grocery list pads were distributed from the Coalition display table. Posters promoting the web sites were displayed at the forum and left behind to put up around Kenora.

The Thunder Bay Luncheon of Hope took place October 17. Over 470 people attended the luncheon that included a guest speaker and display tables. Every participant received a package of promotional materials that included the monitor stickers and grocery pads as well as materials from other Coalition partners. The Coalition also participated in the exhibit displays.

In addition to the brochures and pads, a full-length 11" x 17" poster was created with the Coalition's

web addresses on tear off notes at the bottom. The posters were provided to all public libraries in the Northwest. Regional Health Unit offices will be provided with a supply of these posters requesting that they be posted in high traffic or appropriate areas around the community. Support groups, Northwestern hospitals, major employee assistance programs, Thunder Bay pharmacies, Northwestern women's groups, and Northwestern Ontario colleges and universities will receive a supply of posters for display. All Coalition partners will distribute the posters within their organizations and branch offices where appropriate. The health planner for the First Nations and Inuit Health Branch, Health Canada, will distribute posters to all nursing stations/health centres in the Thunder Bay, Sioux Lookout and Moose Factory Zones.

Objective 2

Strengthen ties and linkages between Coalition and other Northwestern communities outside of Thunder Bay. Develop new linkages.

Prior to their participation in this project, the Thunder Bay Breast Health Coalition based in Thunder Bay primarily planned activities specific to Thunder Bay and surrounding district. This project involved direct consultation with communities in and around Thunder Bay and forged linkages with the Kenora Keeping Abreast Coalition, the Dryden Breast Cancer Support Group, and key personnel at the Thunder Bay District Unit Health and Northwestern Health Unit offices present in every community where consultations were held. In addition, the consultation held in Manitowadge resulted in the creation of a new support group who may be participating in the project by developing their own web page on the site (see *Objective 1, Activity 6*, page 16). The public health nurse in Manitowadge is invited to a local fund raising event and will create a breast health display that features information about the web site. The Coalition's participation at the meetings in Dryden and Kenora was the result of invitations extended to the group by those local community personnel who had participated in the community consultations.

Objective 3

Implement Virtual Community Model in other areas in Ontario

The private "Virtual Community for Breast Cancer Information and Support" was created in May, 2003. A summary of the activity on the site is below on page 25.

Key Findings and Recommendations

The Thunder Bay Breast Health Coalition began the Northwestern Ontario web site project with several key advantages over the Sudbury Regional Breast Health Coalition who sponsored the pilot project. The group had:

- functioned as a Coalition since 1993, meets regularly, sponsors forums, develops resources and is allied with provincial and national breast cancer initiatives and research projects;
- already forged some linkages to regions outside Thunder Bay;
- worked with an experienced project coordinator who had hands-on experience with similar type of project;
- worked with a web developer on the creation of a breast health web site previously;
- developed a web site from a printed pamphlet before and was aware of challenges in presenting information in web format;
- agreed to an initial project proposal for English language content only; and,
- documentation of tips, tools and trials from the Sudbury Pilot Project—many key items such as the policies and procedures, evaluation questionnaire(s), focus group documentation, and the

communications support plan were adapted or revised by the Thunder Bay Breast Health Coalition.

Conversely, the Coalition faced several disadvantages:

- the group agreed to tackle the project within the limits of the original timetable prescribed for the project, even with a three-month extension, the work schedule was an aggressive six months;
- the SARS outbreak in Toronto in March/April 2003 forced a one-month delay of the community consultations and created difficulties for the health care staff on the Coalition to participate at meetings;
- without institutional support of NWORCC for technical support of the project the group had to assume sole responsibility for the web site in long range planning and continue pursuit of other partners;
- ongoing changes at the NWORCC meant assistance in confirming information links and updates were impossible at the time the web site was being developed--the Centre is physically moving to a new location in either the spring or fall of 2004 and, though the NWORCC web site is slated to undergo major changes, a timetable had not been determined;
- many patients in the Northwest are referred out of province for treatment which created the challenge of providing detailed information and links to treatment centres in Manitoba;
- the ongoing constraints on the health care system became evident as the Coalition experienced difficulty in enlisting assistance from local and regional health care workers in confirming resources within their communities—one member reported that if time was required of employees to participate on committees and/or task forces, that contribution had to be budgeted within the institution's long range plans or the time may not be made available;
- requests from the community consultations conducted during May added considerable content to the web site that is was not available online or from any one source; this necessitated research on local resources for 20 communities, and dependence on key informants within those communities for assistance—keeping this information up-to-date will continue to be a challenge;
- follow-up work on the BSE web site project including the launch of the French language BSE site and final report to its funding body (the Canadian Breast Cancer Foundation - Ontario Chapter) coincided with the launch activities and the BreastHealth Northwest project deadline—every other week the group met for between two to two and a half hours to review the two web projects; and,
- assuming responsibility for a project of this magnitude on the heels of the BSE web projects caused a significant pressure on some Coalition participants and it was clear as the project concluded that several members were suffering fatigue and stress due to the enormity of the task.

Flexibility within the grant's budget extended the Project Coordinator's contract and alleviated some pressure on the Coalition to complete updates and additions to the web site. The web site, which has been available to the public since the spring, was largely completed at its launch at the beginning of February. A casualty of this work may be the burden placed on the same Coalition volunteers who participated on the task force. Clearly a major challenge for both volunteer Coalitions in Sudbury and Thunder Bay will be preserving their own Coalitions' vitality with the challenge of ongoing maintenance of the web sites. Unlike a printed resource or an "event" project, online resources require constant monitoring, updating, and review. The Coalitions will need to rely on the continued support of their respective employers to support the project, the continued energetic participation of those volunteers in updating and responding to questions/comments on the web sites, and the time and resources to continue to develop the sites as sources of information and information sharing with the other community organizations in the region. OBCIEP continues to act as a support for these projects.

A number of suggestions arose from the experience of the working group and community consultations in the Northwest:

1. The findings of the community consultations from Sudbury and Thunder Bay were essentially the same. Women want practical information—where to park, where to stay if you must travel for treatment, where to get a wig, etc.—as well as the current medical information that is readily available from other credible, online sources. In retrospect the community consultations could have been consciously directed to identifying and meeting with key informants in the community for buy-in and assistance with the research. During these meetings, the "what's missing?" questions could have received more attention. This would have more clearly identified barriers to care and an assessment of community needs that could be brought to appropriate stakeholders and partners.
2. A group that assumes this type of project in the future should form a working sub-committee from the outset. Frequent meetings caused burnout for the entire group. Many of the members seemed to become overwhelmed with the day-to-day details of the project and over the course of the activity became less involved. Splitting the work so that smaller groups focussed on different progress points on the task (i.e. design, content layout, specific content, etc.) may have lessen the burden on the whole group and encouraged greater feedback towards the conclusion of the project.
3. There are a number of new software programs (e.g. the Core CMS system developed by Norlink or the RedDot system developed by Hummingbird used by Cancer Care Ontario) that offer a user-friendly alternative to using HTML coding for web site development. Organizations creating or adapting web sites should be looking to this type of web creation so members without extensive computer knowledge can easily create and maintain the site.
4. A web site and framework for community web pages are now in place. Consideration should be given to bringing community representatives together to a central location for further promotion and training on the web site. Funding could be provided to local representatives to develop a local web page within their own community. With greater involvement at the community level the regional partnership network will improve and may lessen the burden on the Coalition to update and research local resources for posting on the web site.

Outcomes

The project lead to a number of significant outcomes that increase the efficiency of information delivery and networking in Northwestern Ontario:

- *BreastHealth Northwest*, www.breasthealthnw.ca, a functioning breast health/cancer web site that includes information specific to residents of Northwestern Ontario and links to credible online breast cancer information and support resources;
- increased efficiency for the Coalition in creation and promotion of two web site projects;
- face to face meetings in communities east, north, and west of Thunder Bay;
- forged linkages to Dryden, Kenora, Manitouwadge, Marathon, and other northern communities;
- created new links to other health care centres such as the mental health facility in Atikokan where the public is free to use facility's computer to browse Internet for health care topics;
- increased links in Northwest to contacts in aboriginal communities;
- provided linkages between support groups and women living in various communities;
- redesigned, revised, and distributed "If You Have A Breast Concern Pamphlet";
- created a database of northern breast health resources;
- new ability to publicize and promote breast health and breast cancer events around the region;
- Coalition participated in numerous events resulting in positive media coverage in Thunder Bay and Northwestern Ontario;

- increased profile of the Coalition and awareness of Coalition's resources and work; and,
- development of a unified and recognizable look in all Coalition resources and materials (BSE web site, CD-ROM, pamphlet, monitor stickers, BreastHealthNW posters, grocery pads, and new BSE pamphlet).

Next Steps

Long-range plans for the improvement and enhancement of the BreastHealthNW web site include:

- review usage statistics shown at www.BreastHealthNW.ca/stats (see sample Appendix XIII) to learn most and least popular web site sections with to continually improve content and presentation
- promotion of other web features such as e-mail alerts and online newsletters. This will allow the Coalition to produce a regular newsletter and send e-mail alerts to consumers and health care professionals interested in joining the virtual community
- an Estrogen Forum is in the planning stages. The web site will allow the Coalition to publicize this and other breast cancer related events. Women can register and pay for events tickets on-line, provide feedback, provide input into what information they would like to see addressed at the forum
- future resources developed by the Coalition will be posted on the web site in a printable format (PDF). This will allow for broader, cost-effective distribution of these resources and will keep the on-line version of these resources up-to-date.

www.BreastHealthNW.ca

Thunder Bay Breast Health Coalition

Breast Health Online

*Breast Health Information
in Northwestern Ontario
is now just a click away.*



At www.BreastHealthNW.ca you can:

- Schedule a mammogram
- Know where to turn if you have a breast concern
- Find help in your own community
- Connect with survivor groups
- Find local events supporting breast health

Breast Health Online

www.BreastSelfExam.ca

www.ExamenDuSein.ca

www.BreastHealthNW.ca

Want to learn how to do Breast Self Exam?
Visit a unique multi-media E-learning website on Breast Self Exam (BSE).

At www.BreastSelfExam.ca you can learn:

- How to do breast self-exam
- The early signs of breast cancer
- What to look & feel for

www.BreastSelfExam.ca

www.ExamenDuSein.ca

www.BreastHealthNW.ca

www.BreastSelfExam.ca

www.ExamenDuSein.ca

www.BreastHealthNW.ca

Websites produced and maintained by the Thunder Bay Breast Health Coalition

A VIRTUAL COMMUNITY FOR BREAST CANCER INFORMATION AND SUPPORT IN ONTARIO

OBCIEP Web Site

The OBCIEP public web site was redesigned in the fall of 2001 and was slated to "go live" in the fall of 2002. At that time Cancer Care Ontario, host of the site, approved a massive overhaul of its information technology and software programs. By agreement OBCIEP, delayed the release of the public web site until the new system was in place. The OBCIEP site at www.obciep.on.ca was one of the first web projects produced by the information technology Cancer Care Ontario staff using new software. As the entire Cancer Care Ontario system (including web, records, document management, etc.) was being evaluated and redesigned, a number of delays in completing and repairing software problems with the site occurred during the months that followed. The site was live in mid-May, 2003, and includes a calendar of events, breast cancer information online resources, OBCIEP activities and Community Capacity building project reports, a bulletin board, and links to over 100 OBCIEP provincial and regional partners. The site also lists Canadian and international sources of general information on breast cancer and breast health.

Virtual Community for Breast Cancer Information and Support

The ultimate goal for a Virtual Community approach is to enhance the capacity of the stakeholder organizations to meet the needs for breast cancer information and support. Its purpose is to use technology as a tool that would enhance collaboration between and among a network of organization/groups with a stake in the provision of information about breast cancer and support for breast cancer survivors. It was anticipated that it would build on the existing context of Internet activity by breast cancer groups and add value in terms of collaborative activity, access to information, and sharing of resources.

In June, individual OBCIEP partners were issued access to the members only or "private" section of the site and information was solicited from OBCIEP regional partners. The section initially included OBCIEP standard information on minutes of Coalition and Operations Group meetings, draft publication policies and procedures, and needs assessments.

The objectives of the Virtual Community (*Virtual Community Feasibility Project: Building Capacity for Tomorrow*, 2000) are noted below with outcomes observed to date:

To enhance shared access to information about breast cancer.

The OBCIEP web site attempts to provide links to all partners' web sites and to current credible sources of information available on the Internet. It uses the Canadian Health Network's criteria for evaluating health information on the web and meets the Health on the Net "HON Code" principles. Links to other Canadian national and provincial web sites are included along with some international links.

To enhance linkages and working relationships between and among local/regional, provincial/territorial, and national groups.

Through the private space, network partners are encouraged to share plans, experiences, documentation of projects, etc., to assist other groups and to share lessons learned. Many groups throughout the province are involved in ongoing or special events planning for education and/or fund raising purposes and there is enormous potential for groups to share information on those activities. The Sudbury Regional Breast Health Coalition, for example, chose to hold an education session on

HRT upon learning of the overwhelming success of the Thunder Bay Breast Cancer Coalition's forum called "Estrogen: What's Hot? What's Not?" held in February 2003. The forum agenda and speaker list was shared on the virtual community along with informal information between the event organizers and the Sudbury Coalition.

To provide access to an inventory of all the players/stakeholders in the network.

The OBCIEP web site strives to present a comprehensive summary of all breast cancer information and support groups within the province. The Canadian Breast Cancer Network has assumed the task of collecting an inventory of groups and services Canada-wide. All OBCIEP network partners are listed on the site with links to web sites where possible. In some cases, breast cancer support groups directed and managed by survivors have chosen not to be listed due to suspension of the group's activity. Each group was contacted prior to the launch to confirm their wish to remain listed.

To facilitate the identification of issues and gaps.

Information and support needs are identified through the OBCIEP Bulletin Board and posting of survivor needs assessments conducted at meetings across the province.

Information gaps also exist among groups and the private space of the OBCIEP web site affords these groups the opportunity to learn and share. One of the first shared documents on the site was the administrative policies and procedures for management of the regional web sites. When policies and procedures for online publication were being finalized for the Northeast and west regional web sites, OBCIEP contacted partners who hosted web sites to share their policies for information. Very few groups had formal written policies and, when the policies for *BreastNorth.Info* and *BreastHealth Northwest* were completed, many indicated an interest in adapting the information for their own use.

To facilitate sharing of ideas and concerns with others participating in network activities (committees/task groups).

A meeting of the OBCIEP Coalition members is scheduled for November 2003, to discuss the virtual community and how groups can maximize its capacity.

To facilitate the development of action plans.

OBCIEP Coalition members review and determine an action plan for the organization on an annual basis. An updated report of progress on activities can be posted online for review by OBCIEP partners and corresponding members. Activities, document or action plan development requiring input from all parties can be facilitated through use of the virtual community which remains of interest to OBCIEP partners only, and not to the public at large.

To hold meetings "on-line" and so decrease costs associated with frequent face-to-face meetings.

The experience of "online" meetings has not been rated highly among OBCIEP partners. Typically partners viewed this method as awkward. Conference calls or in-person meetings are seen as much more practical and enjoyable compared with reliance on hardware and software equipment and the skill of participants to conduct online meetings. The Members Only web site affords participants the option of visiting the site at their leisure and viewing documents of interest rather than receiving them unsolicited via e-mail.

Key Findings

Between 1999-2000, when the Virtual Community Feasibility Project was conducted, and 2002-03, when community consultations were completed for the regional northern Ontario web sites, there was a remarkable shift noted in the familiarity and use of electronic information and communication tools. In 1999, over 80% of the support groups surveyed indicated that access to the Internet, set-up concerns, training, and hardware, software and maintenance costs were perceived barriers to participation in a virtual community for breast cancer (*Virtual Community Feasibility Project, Building Capacity for Tomorrow*, 2000). In 2003, almost all of OBCIEP's 70+ support group partners have contact people who have an e-mail address and 31 of OBCIEP's 37 Coalition partners sponsor their own web sites. The majority of the breast cancer survivors who participated in the community consultations in Northeastern and Northwestern Ontario, many of whom are 60 years of age or older, indicated some familiarity with the Internet and e-mail. Those who did not consider themselves users of online information sources indicated an indirect use through information provided by family members, friends or organizations like the Canadian Cancer Society that regularly uses online information sources. Information needs for people in outlying areas included general information about cancer, but repeatedly indicated a need for information specific to their region. Some conclusions are summarized below:

- use of the Internet is wide-spread although often indirect; some may not access it directly, but most people receive information from online sources from family, friends, health care providers and support services;
- provision of information resources online is an efficient, timely and relatively inexpensive method of information dissemination compared with print media; however, some printed information with in-person support is also required;
- people who are familiar with online cancer information also want community/local/regional resources and links; and,
- a "one-stop shopping" approach is preferred that includes tips and information for those who need to travel to treatment centres outside their areas.

First Nations communities present unique challenges in that the approach to illness and learning about illness is vastly different from the "modern" western approach. Information online tends to repeat the style and presentation of printed material that includes some graphics but much text—to appeal to an aboriginal audience information may have to be revised to focus on graphics. In addition, computers are not common on reserves and economics preclude many families from owning the equipment and opening Internet accounts, though many health care centres on reserves provide access to the web. While these challenges were beyond the scope of the current project, key contacts were made in First Nations communities particularly in the Northwest. The Thunder Bay Breast Health Coalition is hoping to work with some First Nations groups to rework some information on *BreastHealthNW* in a format specifically directed to aboriginal women.

While the majority of OBCIEP's network partners have access to the OBCIEP virtual community at www.obciep.on.ca, there is an ongoing challenge to educate and communicate the benefits of the tool to all partners. OBCIEP will be meeting with its Coalition partners in early November 2003, to develop an action plan around the further use and promotion of the virtual community tool.

Project Outcomes

The key outcomes of the project are:

- functioning web sites in the Northeast and Northwest Ontario (www.breastnorth.info and www.breasthealthnw.ca) that include local/community information relevant to those dealing with breast cancer, links/information to local support resources, links to credible sources of breast cancer and general cancer information and provincial supportive care resources and other relevant

- sites;
- a structure, process and background documentation (including evaluation tools) to assist other groups to create/revise local or regional breast health/cancer related web sites; and,
- a provincial virtual community for breast cancer.

One of the primary outcomes for this project was to move the focus of collaborative activity surrounding breast cancer information dissemination and identification of information gaps to the regional/local level. The implementation of two new regional web sites and the creation of a working virtual community for breast cancer information and support organizations has offered two new valuable resources for northern Ontario but significantly in the process of consultation and development has introduced new local partners that have strengthened the Coalitions in Sudbury and Thunder Bay. The creation of regional web sites for Northeastern and Northwestern Ontario has increased both the number and nature of partnership links within those regions.

The provincial virtual community has been created and access has been provided to OBCIEP's Coalition partners. The virtual community approach will be utilized as a means to enhance the timely dissemination of information to breast cancer organizations and individuals across the province. It includes all current OBCIEP information resources, links to partner and other web sites, access to "private" documents and information contributed by OBCIEP and its partners, as well as a bulletin board and e-mail address accessible to the general public. OBCIEP continues the province-wide implementation of the virtual community model to:

- enhance the working relationships between and among local, regional provincial, and national groups;
- decrease the isolation of women and support groups, particularly those in outlying areas;
- ensure that breast cancer survivors are involved in the work of the breast cancer network;
- increase the efficiency of the work of breast cancer networks; and,
- encourage the integration, coordination, and use of existing resources as effectively and efficiently as possible.

Population Health Determinants

The creation of the Virtual Community framework builds on the work accomplished at the Think Tank in 1999, the feasibility study of 2000, and the Community Conversation Gatherings of 2000-01. The needs assessments completed during those projects highlighted an ongoing demand by people affected by breast cancer for current, credible information on medical, emotional and support concerns introduced by their disease. The creation of two new regional web sites for Northern Ontario and a provincial Virtual Community addresses a number of determinants of health:

Social Support Networks

The current project created two new regional web sites with connections to local and remote locations. A new support group developed in Manitowadge and the network of support and information groups expanded to include support groups across the north. It has provided new ways of communicating and sharing information through web links and through identification of key networking partners across the province. The new web sites provide links to general information on cancer but more importantly provide information on many types of support services within specific communities in the regions. The development of the web sites has also provided invaluable opportunities for face to face meetings between and among breast cancer survivors, newly diagnosed women, and health care providers. It also provides an online forum for information sharing among the breast cancer information and support groups throughout the province, including those communities isolated in remote areas of the province.

Personal Health Practices and Coping Skills

The new web sites provide information links to credible health promotion information provided in a user-friendly format fashion. The sites provide preventative health information and connections to support networks available in person, by telephone, and through chat rooms and other online connections and linkages to direct support within individual communities

The process of developing the web sites has provided a vehicle to inform health care professionals about breast cancer patients' needs and concerns for specific medical, emotional, and support information. In increasing survivors' and the public's knowledge of cancer treatments, preventative health issues, and support services, people are more informed about where to seek information to make the best choices for their own health care and treatment options.

Next Steps

Activity will now focus on maximizing the use of the virtual community tools in place. The development of an action plan for the provincial virtual community will highlight where progress to date has been slow. This includes the day to day work of the breast cancer network where use of the virtual community can offer:

- access to lists of new or revised resources/activities breast cancer organizations are currently developing;
- identifying gaps in resources;
- what successes/challenges partners have faced and what were the outcomes—i.e., what works, what does not;
- ability to distribute draft material for review and comments; and,
- develop action plans.

Network partners will be encouraged to contribute and share information on the virtual community to enhance the communication and learning potential of this new resource. OBCIEP looks forward to continuing the implementation of the tool to all OBCIEP Coalition network partners and grassroots groups.

www.obciep.on.ca



APPENDICES